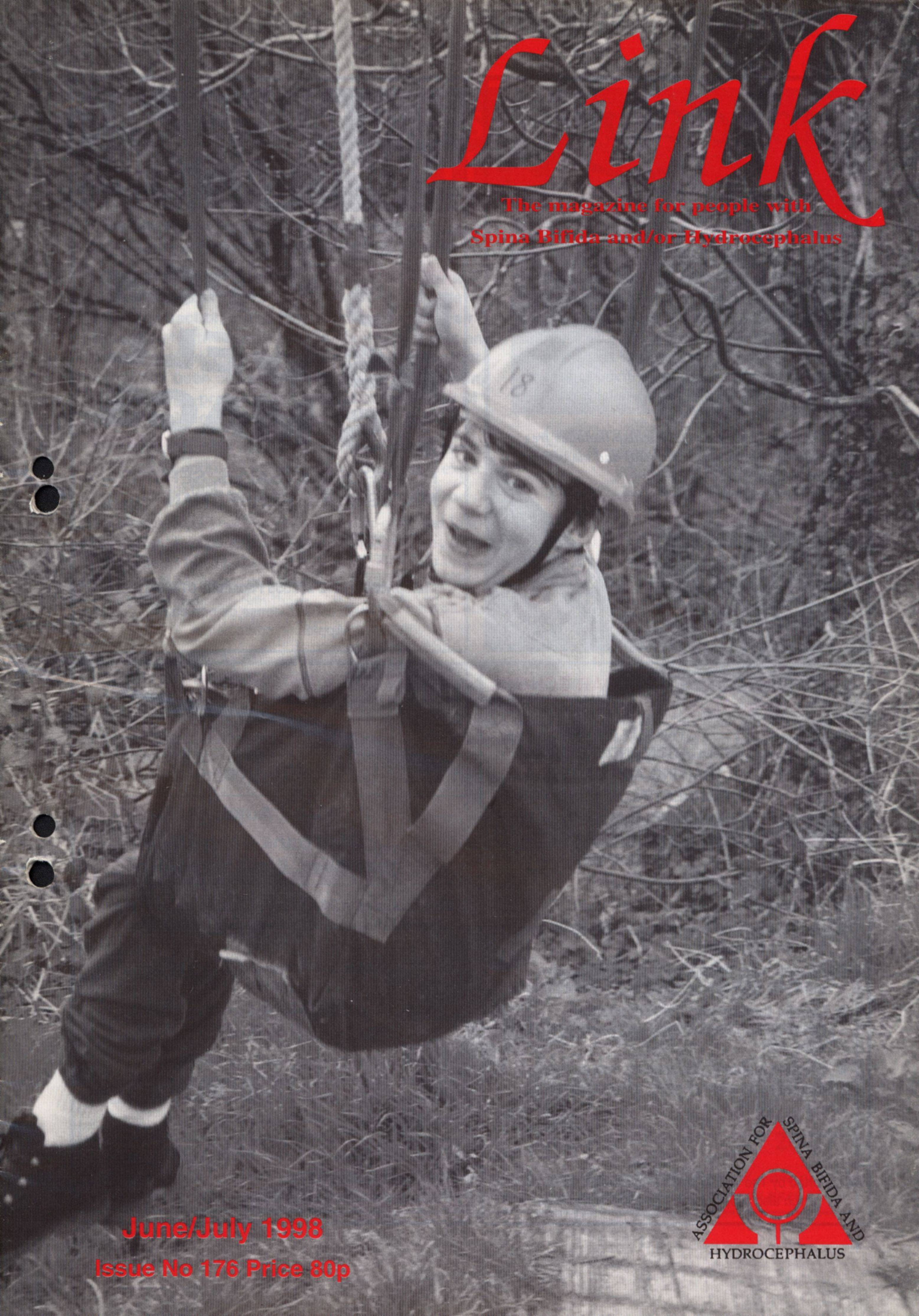
Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



June/July 1998
Issue No 176 Price 80p

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

novacare

PRESCRIPTIONS TO YOUR DOOR

“Thank you for the speedy, efficient, courteous and friendly service – such a refreshing change.”

TPN, AVON

This compliment from one of our many letters of appreciation is a typical response to Novacare's prescription delivery service throughout over nine years in this specialised healthcare field.

As a totally independent supplier we cater for all stoma and continence appliance needs including catheters, sheaths, leg and night drainage bags as well as the new anal plug, now available on prescription for the first time.

Our completely free service also includes free extras to aid application, disposal and cleansing. Ask for details.

For advice or ordering call us free on
0800 21 22 58
ask for Hilary or Chris

or write to Novacare, FREEPOST
Newport, Shropshire, TF10 7BR

or you can E-mail us on:
prescriptions@novacare.enta.net

FREE INTRODUCTORY OFFER! a discreet Home and Travel Holdall with your first prescription

COMPUTER SENSE

Computer Sense now offers a highly-professional sales and advice service to firms which use PCs as well as Apple Macs.

The unique difference still is that all profits generated by Computer Sense go to ASBAH.

The success of Computer Sense, which is wholly-owned by ASBAH, directly benefits the charity.

NOW PCs AS WELL AS MACS

PC/APPLE MAC SALES, SERVICE – MAKES MORE SENSE THAN EVER!

Computer Sense Ltd
Grovelands Business Centre, Boundary Way
Hemel Hempstead, Herts HP2 7TE

Telephone 01442-252555 Facsimile 01442-219222

E-mail: csl@co-sense.demon.co.uk
Applelink: comp.sense

LORD MAYOR TRELOAR SCHOOL

Froyle, Alton, Hampshire GU34 4LA

exists to provide EDUCATION, INDEPENDENCE TRAINING AND CARE IN A RESIDENTIAL SETTING FOR YOUNG PEOPLE AGED 5 - 16 WITH PHYSICAL AND LEARNING DISABILITIES

- Full National Curriculum access
- Full range of subjects to GCSE level
- Modified curricula available for students with learning difficulties
- All staff have experience of working with students with Spina Bifida and Hydrocephalus
- On-site therapy and medical support, rehabilitation engineering and experienced care staff
- School Chaplain; counselling and careers advice services

For further information, please contact:
Admissions Officer
on 01420 547425

(Supported by The Treloar Trust, Registered Charity 307103, which also supports a further education college)

‘SUMMER EXPERIENCE’

for 12 – 16-year-olds

24th – 27th August 1998
Nell Bank Centre,
near Ilkley, West Yorkshire

This summer, ASBAH is organising an exciting residential course for young people. The aims of the course are:

- to allow groups to share and learn from each other
- to enjoy new and exciting experiences
- to have a good time!

Activities will be lively and mainly outdoor (weather permitting), with lots of opportunities for socialising. A team of student helpers will act as buddies to people on the course.

Cost: £80. Booking forms from: ASBAH House North, 64 Bagley Lane, Farsley, Leeds LS28 5LY. Further details: Joan Pheasant (0113) 255 6767.

Two bright lights shine on ASBAH

THE SPOTLIGHT will be shining on ASBAH at least twice this year as we feature in two top events.

Wheelchair racer Tanni Grey – *pictured right with Prime Minister's wife Cherie Booth* – won the women's section of the Flora London Wheelchair Marathon for the fourth time in six years. It was an even greater achievement when you consider that Tanni has been combining wheelchair race training with the high-profile job of project co-ordinator of the BT Athletics Scheme.

Tanni Grey (right) meets Cherie Booth after winning the women's section of the 1998 London Wheelchair Marathon.

Photo: © Graham Bool Photography 1998

Seven non-disabled people raised money for us in the 1998 Flora London Marathon, which this year is expected to raise more than £11 million overall for charity.

Lucy Stevenson of London; Phil Robinson of Sleaford, Lincs; Amir Bhati of Ilford; J W MacLean of Gloucester; T McVaddy of Chelmsford; Louise Mackeson-Sandbach of Guildford and Gill Daly of London all contacted us saying they had places in the 26 April event and would like to raise money for us. Two other people fundraised for us in events on the same day – Andrew Hunter, of Romford, Essex, who took part in the London Mini-Marathon for 11-17 year-olds; and John Clark, of Sheffield, who entered the Sheffield Half Marathon. Very many thanks to you all!

But more media time, and even more money, is set to be ours in July when ASBAH – and a handful of our service-users – are given daily breakfast-time coverage for a week as part of GMTV's *Get Up & Give Appeal*. You, too, can join in the fun on Wednesday 15 July at GMTV's Family Day for ASBAH at Alton Towers. *Turn to the centre pages of this issue of* Link *to see how you can win free tickets for a fantastic live TV show and day out.*

Contents

ASBAH is a registered charity

E-mail: postmaster@asbah.demon.co.uk Find us on the Web – http://www.asbah.demon.co.uk/

Cover: Michael Chambers, aged 13, smiles as he embarks on the 'death slide' – one of the activities in the Looking Good, Feeling Good *course in Cornwall. Full story on page 11.*

STAFF NEWS .... STAFF NEWS .... STAFF NEWS....

● PETRINA Noyes is the new national specialist adviser (education) following the retirement of Peter Walker.

The mother-of-one is a former teacher of modern languages and special needs. She has worked in mainstream schools in the North East and the Midlands.

In her last job, she worked in a unit for special needs children at a comprehensive school, as well as teaching modern languages to mainstream pupils.

"I was looking for a new challenge which built on my experience in special needs education. As a specialist adviser, I look forward to providing a service to professionals, using my expertise to help parents and provide children with the best opportunities for education."

Petrina – who started at national centre in Peterborough in April – works on Tuesdays, Thursdays and half-day on Wednesdays.

● FORMER staff nurse Sue Ingham takes over as specialist adviser (medical) for the Northern Region after her predecessor, Geraldine Binstead, relinquished this role.

Sue, who has 20 years' experience as a staff nurse and 18 months' experience as a practice nurse, will be working part-time – initially on Mondays, Thursdays and Fridays, and based at the Northern Region office in Farsley, Leeds.

A single mother who lives in Farsley, Sue spends much of her spare time with her 14-year-old son – watching him play football for a local team and helping on the sidelines, and accompanying him to watch his favourite team, Leeds United, in action.

"When I applied for the job at ASBAH I saw it as a challenge and a way of helping people and giving them a focus at the times when they feel helpless," Sue said.

● Although Geraldine has given up the specialist adviser (medical) post, she continues as part-time area adviser for North Yorkshire, Middlesbrough, Redcar and Cleveland.

● With the retirement in April of part-time area adviser Sue Patten, there is a new arrangement of cover in Kent.

Full-time adviser Lynda Atkins takes over the whole of Kent and a half-time assistant will be appointed – funded by Kent County Council and Kent ASBAH, and employed by Kent ASBAH.

See page 10 for more news about Kent ASBAH.

Social security win: one up for ASBAH

By Liz Cawthorne

A FAMILY, who were repeatedly turned down in their application for Disabled Living Allowance (DLA), have won £4,000 in back-payment after the Social Security Commissioners found the tribunal to have made an error in law.

It was the first time that ASBAH had taken a benefits case to the Social Security and Child Support Commissioners, but East Region co-ordinator and benefits adviser, Mary Malcolm, was confident the Carver family should win – however difficult the route proved to be.

Parents Darren and Tracey, from Nottingham, are said to be 'over the moon' with the result, which took two and a half years to secure for their daughter Amy *(pictured)*.

Their ASBAH adviser, Janet Stewart, said: "I know the money will make a tremendous difference to them and that they are very pleased with the outcome.

"We had a few hairy moments, but I was determined not to let this one drop. All credit to Mary, who did a lot of research and visited the family several times, and who stuck in there and tackled the situation, even though it was unknown territory. We both felt Amy was entitled to Disability Living Allowance (care component)."

Mr and Mrs Carver applied for DLA back in June 1995, when Amy, who has spina bifida and a left foot which turns inwards, was nearly three months old.

Mrs Stewart told the adjudication officer that physiotherapy had to be performed on Amy's left leg at every nappy change. There were also medical appointments to go to, and attention given to Amy in the night if she needed turning.

After being turned down by adjudication officers on two occasions, Mrs Stewart went to the disability appeal tribunal in June 1996 – by which time Amy was 13 months old.

The tribunal turned down the Carver's claim for DLA, saying that Amy did not require attention or supervision substantially in excess of that normally required by a child of that age.

So Mrs Stewart enlisted Mrs Malcolm's help in appealing to a higher body than the tribunal – a court of law in London called the Office of the Social Security and Child Support Commissioners.

Mrs Malcolm, who became the family's representative, said: "For a case to be submitted to the Social Security Commissioners, there has to be an error in law. The grounds of our appeal were that the tribunal had failed to establish sufficient finding of fact and inadequate reasons given for its decision.

"The Social Security Commissioners considered the facts of the case and our appeal was upheld. The decision of the original tribunal was set aside and would be reheard by a new tribunal.

"The case went back to tribunal in March and the tribunal decision found in favour of the family's application for middle rate DLA – reversing their former decision."

Officers & Staff

Patron:
HRH The Duchess of Gloucester, GCVO

President: Dr Jeffrey Tate, CBE

Chairman: Mr Godfrey Bowles

Hon Treasurer: Mr Charles Ortner

Executive Director:
Andrew Russell, MA

Finance Director:
Derek Knightbridge, FCCA

Assistant Director (Personnel):
Paul Dobson, BA (Hons), FIPD

Assistant Director (Services):
Teresa Cole, MICA

Services Manager: **Milly Rollinson CQSW**

START Manager/Northern Regional Co-ordinator:
Joan Pheasant, NNC

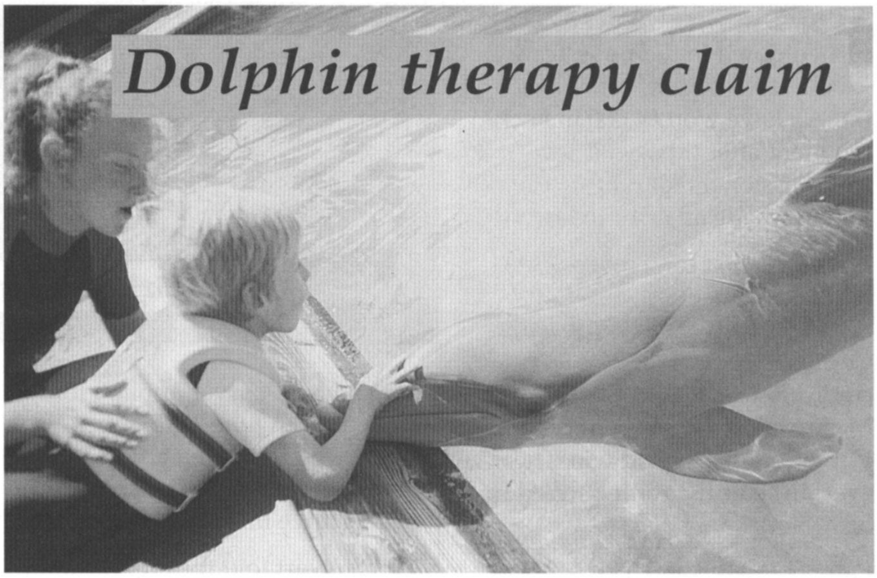
Senior Adviser – Health and Policy Issues
Rosemary Batchelor SRN FETC

Appeals Manager:
Donna Treanor

Publicity Manager:
Tony Britton

Research and Information Officer:
Gill Winfield Cert Ed

Dolphin therapy claim



Travis Matthews strokes a dolphin's head in a therapy session in Florida

A MOTHER says her son is experiencing lasting benefits after undergoing therapy sessions in Florida with dolphins.

Kathy Matthews was reduced to tears when she saw eight-year-old Travis, who has hydrocephalus and mild cerebral palsy, walk without callipers for the first time on the first morning of the therapy.

She claims Travis was spurred on by the presence of the dolphins, the warm weather and the enthusiasm of the therapists – in contrast, she says, to the negative attitude she has experienced in Surrey.

"The therapist asked Travis if he wanted to walk and he said: 'Let's walk to mum.' I turned round and he was walking on his spindly legs with the therapist holding him under his arms. The therapist gave him the confidence to walk and everyone was clapping and cheering. He may just have been showing off, but I didn't care. It was wonderful. I don't find this positivism over here; we've come back to frustration."

After several sessions on the dock, which included stroking a dolphin's head and holding a hoop for the dolphin to jump through, Travis was eventually allowed into the water, assisted by a therapist and a dolphin trainer.

Mrs Matthews said: "Travis's attitude to the dolphins confirmed how intelligent he is. He didn't love them; he didn't laugh and pat them but was very wary of them. He was aware of this very large mammal in the water and tentatively put an arm out to touch it.

"The therapist held Travis up in the water and made a circle, and the dolphin copied it. Then he held on to its fin and was pulled along for a ride.

"Over the two weeks we were there, he got used to them and they relaxed him – I think they must have got through to his brain. It just seemed as if something in his brain clicked into place."

Mrs Matthews says improvements in Travis's behaviour, alertness, mobility, memory and speech are continuing to take place now that he is home again in Ham, Surrey.

"It's unbelievable but he now talks in sentences, is calmer and more confident and is willing to sit down at the table with mainstream children and eat nicely. He wouldn't do this before as he knew he was different.

"He still can't walk without support but he can sit down on the floor, cross-legged and his balance is beautiful.

"He will now focus on you now. He will look straight at you when he is talking and understands when I tell him not to shout."

Mrs Matthews thinks the full effects of the therapy will take up to two years to show, after which time she plans a return visit. Nine 40-minute sessions cost £4,000 which, along with money for other expenses of the trip, took Mrs Matthews 18 months to raise.

"I want to give time for the therapy to settle and keep up the exercises they gave Travis to do daily."

She added: "We didn't want miracles but the effect of the dolphins has been simply marvellous."

Editor's note: Although children with cerebral palsy apparently benefit from dolphin therapy, there has been no research to show that it benefits children with hydrocephalus. This is a very personal account of apparent success with one child.

Accessible bridge battle lost

A FIGHT to make a footbridge along the Thames Path National Trail accessible has been lost.

Last ditch developments, involving the Minister of the Environment – who called in the planning papers for the steeply stepped bridge – and a withering letter from Equal Opportunities Minister Alan Howarth failed to have any effect.

The weight of other arguments prevailed – that a sloped bridge at Bloomer's Hole, near Buscot, Oxfordshire, would not only cost more but would extend further into environmentally sensitive water meadows.

Mike Bruton, chairman of the Disabled Drivers' Association's countryside access group, said: "The battle is lost but we gave them a good run for their money. We are a minority interest group and, unless we have a legal right to access, we cannot stand up and claim an equal interest to others."

Who's being 'bipped'?

THE Benefits Agency is at present reviewing the Disability Living Allowance (DLA) awards of over 400,000 disabled claimants.

The review exercise is a product of the previous government's anti-fraud drive. The review was put on hold during the Election campaign but the new Labour Government has resumed the exercise more or less unaltered. In recent correspondence between ASBAH's executive director and Harriet Harman's office, they are now denying that this is part of an anti-fraud drive, but is to ensure that disabled people receive the right amount of Disability Living Allowance.

The project has been in operation since May 1997 and is due to run for two years. The people targeted are adults receiving:

High Rate Mobility Component &
High Rate Care Component
– receiving a visit

By Mary Malcolm

High Rate Mobility Component &
Middle Rate Care Component
– detailed questionnaire

Exempt categories

The following groups of Disability Living Allowance recipients – expected to total around 15,000 – are excluded from the review and should not have to complete a questionnaire or have a visit:

- People who are terminally ill and are receiving payments under the special rules.
- People who are both deaf and blind
- Double amputees
- People who come within the Department's definition of severe mental impairment
- People who are quadriplegic/ paraplegic
- Those people with an underlying entitlement but who are not actually being paid the benefit, ie, people in hospital or residential care.
- Children under 16.

According to the DSS: "Benefit Integrity Project cases will be identified each month by a computer scan. This will exclude cases on

continued on page 8

Help & Advice

Members seeking help and advice on any matters should make initial contact with ASBAH as follows:

Greater London, Berks, Hants, Kent, Surrey, West and East Sussex

ASBAH South East, 209 Crescent Road, New Barnet, Herts EN4 8SB.
Tel: (0181) 449 0475. Fax: (0181) 440 6168. Regional Co-ordinator:
Jo Francis.

Bedfordshire, Cambridgeshire, Derbyshire, Essex, Hertfordshire, Lincolnshire, Leics, Northants, Nottinghamshire, Norfolk, Suffolk

ASBAH East, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.
Tel: (01733) 555988. Regional Co-ordinator: Mary Malcolm.

Northern Ireland

ASBAH Northern Ireland, Graham House, Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8BH. Tel: (01232) 798878.
Fax: (01232) 797071. Regional Co-ordinator: Margaret Young.

Cleveland, Cumbria, Durham, Greater Manchester, Humberside, Lancs, Merseyside, Northumberland, Tyne & Wear, North Yorks, South Yorks, West Yorks

ASBAH North, ASBAH House North, 64 Bagley Lane, Farsley LS28 5LY.
Tel: (0113) 255 6767. Fax: (0113) 236 3747. Regional Co-ordinator: Joan Pheasant NNC.

Rest of England and Wales

ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ.
Tel: (01733) 555988. Fax: (01733) 555985.

ASBAH welcomes and appreciates the support of its commercial partners.

***Larkhall Natural Health** gives us 10p from the sale of each container of Cantassium Folic Acid tablets. These can be obtained in chemists and health food shops.*

***AlphaMed Ltd** makes a donation for every prescription order received, as a result of ASBAH's introduction, for continence and medical equipment supplies. Tel services floor, 01733-555988, for introductory Freepost envelope. Prescriptions for drugs or medicines should not be sent to AlphaMed.*

Who's being 'bipped'? from page 7

which action was completed within the last 12 months, and include new and renewal claim determinations, reviews and appeals."

Early impressions of the Benefits Integrity Project at 31 October 1997 reveal that 45,000 questionnaires have been issued of which 40% (18,000) have been cleared; of the 7,500 visits conducted so far, 2,500 have been cleared. Overall, fewer awards have been decreased than anticipated with more awards staying the same.

Summary of OUTCOME at 31 October 1997:

Expected	Visit	Postal Enquiry
No change	88%	73%
Increased	0%	10%
Decreased	12%	17%
Actual		
No change	92%	86%
Increased	0%	3%
Decreased	8%	11%

Source: RADAR December 1997

The vast majority of disabled people are (as is proved by the project so far) receiving the benefit to which they are entitled. We know from quite a number of ASBAH members that an initial decision to reduce benefit can often be reversed if challenged in a factual, well-argued way.

Entitlement is based on the effect of a disability, and not simply the fact of a disability, and this makes the whole matter very subjective. We will try to ensure that any review under the Benefits Integrity Project is done fairly, to prevent loss of benefit on which people rely.

In February 1998, the Government announced 'extra safeguards' to the procedure to reduce the number of disabled people wrongly losing Disability Living Allowance as a result of the project. Official figures show that one in five people who had lost benefit in this way had it reinstated on appeal. So, in future, Disability Living Allowance will not be cut on the basis of the claimants' evidence alone. Instead, extra information will be first sought from a third party like carers, General Practitioners, etc.

This change to procedure may reduce the number of wrong decisions but all disability organisations believe it is not a satisfactory way of assessing people's entitlement to Disability Living Allowance. RADAR, the umbrella organisation for disability organisations, is continuing to put pressure on the Government to suspend the Benefit Integrity Project.

If you have had a bad experience through the project, please write and tell us and we will try to advise, and pass the information on to RADAR to help with the national campaign.

● ***Mary Malcolm is ASBAH's national benefits adviser and co-ordinator of our Eastern Region.***

£50pw worse off after being 'bipped'

Georgie Fryer – her Disability Living Allowance was cut after a three-year review

A MUM who uses a wheelchair and her husband, who is her carer, have had an overall cut in benefits of £50 per week after her claim for Disability Living Allowance (DLA) was reviewed.

Georgie Fryer did not know she had spina bifida occulta until she had her fourth child in 1995. However, she had noticed a deterioration in health from the time she injured her back and lung in a car accident in 1991.

Today, the 32-year-old is in constant pain with a tethered spine and frequent breathlessness. Exertion causes headaches and dizziness. Georgie's mobility is restricted and she needs help bathing, dressing and getting up. Her food has to be cut up for her as it is her left side which is most severely affected. She takes painkillers to sleep and her husband Martin has to help her in the night, if she gets pain or cramps in her legs, or needs to go to the toilet.

Three years ago, at tribunal, she was granted the high rate mobility component and high rate care component of DLA.

At a review in March, Georgie was sent three forms to fill out. Her GP also asked her to help him fill out a medical assessment.

Weeks later, with no explanation or warning, Martin was handed Georgie's benefit book with the revised rates at the Post Office.

The £37 per week cut – from high to low rate care component – also means the couple will lose £13 a week Disability Premium – a combined loss of £50 per week.

Another trigger benefit of £35 – Invalid Care Allowance – lost in the change will, fortunately for them, be made up in Income Support.

Georgie, of Penryn, Cornwall, said: "It's shocking. It is a huge fallacy of the system that they can slash your benefit without telling you. This is an injustice to me.

"DLA should be granted for life when you have a condition that will not get better."

Georgie plans to appeal, but it could be a year before her case is heard at tribunal.

Wheelchair centre changes course after ASBAH acts

A WEST Country NHS wheelchair service changed its policy – after ASBAH complained that its contracted supplier was charging a wheelchair voucher customer exceptionally high rates for maintenance on his new £1,250 wheelchair.

The customer, who lives in Dorset, phoned ASBAH for advice after being told to pay £800 for a compulsory insurance and maintenance package on his new wheelchair.

ASBAH's national mobility adviser, Tim Leech, claimed that East Dorset wheelchair service was breaking the rules of the wheelchair voucher scheme by demanding payment up-front, before they issued the wheelchair to their customer.

He said NHS Executive guidelines covering the use of the 'independent option' under the wheelchair voucher scheme state that it is the responsibility of users to arrange their own wheelchair insurance, thus opening the door for them to 'shop around' for the best deal.

"Their Dorset customer was offered a voucher which covered the full cost of his new wheelchair, but was then told to pay £800 to cover five years' maintenance and insurance," said Tim.

"The chair was withheld by the supplier until the user could pay the £800 demanded. This was totally wrong; in effect, it was a private supplier withholding equipment which had been prescribed to meet someone's medical needs."

He added that the chair in question – a lightweight import from America called the "Quickie" – was known for its reliability and resistance to breakdown, and often went for three years before needing repairs. Specialist disability insurance firms, like Fish, would quote £45 a year to insure similar models.

Paul Lumsden, general manager (community hospitals) for Dorset Healthcare NHS Trust, said: "When we became aware of the difficulties of this particular user, we decided to bring forward our maintenance review and introduce a number of options to suit the individual."

He said the East Dorset wheelchair service had been operating the wheelchair voucher scheme for just six months before the complaint. It now intended to give information and support to its customers – so they could make informed choices about maintenance.

Mr Lumsden added that the service would extend its list of contracted suppliers, which will help to push down the prices of maintenance packages.

The customer with the complaint, who has spina bifida, declined to comment.

Radio 4: what's new in its coverage of disability issues

MORE details are emerging from the BBC about how its new Radio 4 schedule will cover disability issues – following the disappearance from the airwaves of the familiar Thursday night fixture *Does He Take Sugar?*

James Boyle, the Radio 4 controller, has already heavily trailed the extended *You and Yours* consumer programme which goes out at noon each weekday as the main source of Radio 4 disability coverage in the future.

The *Does He Take Sugar?* team – led by Colin Hughes – has moved over to the consumer programme and gets the chance to deal with wider issues while encouraging others to understand disability.

Less well known is the BBC's intention to transmit occasional programmes about disability during the afternoon on Radio 4, which, says the BBC, will catch a potential audience four times bigger than was available to *Does He Take Sugar?* The first batch of these programmes has already been commissioned. A mini-series on Hollywood's treatment of disability is in the pipeline, although transmission dates have not been announced. Other programmes are being made and they will be broadcast at different times of the day.

The popular *In Touch* programme, for blind and visually-impaired listeners, is still going out in its Tuesday evening slot, although it has been shortened to 20 minutes.

You and Yours has not yet taken over the mantle of *Does He Take Sugar?* as the place on the airwaves where disabled people gather to mull over the events of the day. But it is early days yet and even a Radio 4 spokeswoman admitted that the schedule is still being bedded in.

Radio 4 plans are well advanced to develop telephone and internet services for disabled people, their families and carers, using the resources of the BBC Helpline in Glasgow. Callers can reach the BBC Radio 4 Helpline on freephone 0800-044 044, which is staffed 24 hours a day, throughout the year.

In a letter to disability campaigners in Coventry, including ASBAH adviser Jenny Green, James Boyle commented: "I can reassure you that, rather than diluting the coverage, Radio 4 will be offering an enhanced service."

New staff as KASBAH scoops Lottery jackpot

A LOCAL ASBAH has won a major award from the National Lottery Charities Board.

Kent ASBAH has been given £78,695 to employ two development workers – to ensure that the needs of its members are being met by the statutory sector.

It was the second time that Kent ASBAH (KASBAH) had put in a bid to the NLCB. Its first application failed, so to then go on and win the full amount of money applied for was an added bonus.

Chairman Pam Gaskin said: "We were extremely surprised to hear that we'd been successful in this application as we had been unsuccessful before, and had been unsuccessful with applications to other funding bodies.

"But having the development workers had been thought about for quite some time before the application was made and, when we read the information about the criteria in this particular round, we seemed to fit perfectly."

As well as filling out an application form, Mrs Gaskin was interviewed for two hours on the phone about the details of the bid.

The two development workers – set to be in post by September – will each have their own areas of Kent, but will be working closely together to sort things out.

One of their first tasks will be to visit as many as possible of the 360 families on KASBAH's books – to find out if all their needs are being met. The workers will also be making links with statutory authorities – the aim being to attract more statutory funding to services for people with spina bifida and/or hydrocephalus and their families.

Mrs Gaskin said: "We conducted a membership questionnaire last year which showed that people wanted to meet more often, so there is a need for more localised meetings.

"These meetings will also help the ASBAH adviser as she will be able to set up surgeries, so cutting down on the time she spends travelling.

"Although the development workers will not be taking on the adviser's role, they will take quite a lot off her shoulders."

Bring me the head of Ironside *by Paul Darke*

IT has been interesting to look at the day-time TV schedules for disability content: primarily the re-runs of American TV serials such as *Ironside, Petrocelli, Quincy* and *The Rockford Files*. I am very fond of them all, especially *Ironside*, and I suspect this is due to remembering them as peak-time viewing when I was a child.

Ironside left a great impression on me then and it still impresses me. This is not to say that *Ironside* or the others were perfect – sometimes they are incredibly crass and naively politically correct – but they were light years ahead of UK TV representations of disability and, tragically, they still are.

One of the joys of all those series was that every season would have at least one disability-orientated plot line. And, of course, Mr Ironside was always in his wheelchair going around San Francisco in the first heavily armoured 'people carrier.' Oh, how I wanted one of those – along with an army of enablers to smooth my path wherever I went. *Classic.*

Each serial disability episode(s) in US TV programmes was influenced by notions of 'mainstreaming' (or what was later called normalisation). All at a time when they were revolutionary new ideals and conflicting with the status quo. All we ever had in the UK were (and still are) victims who are little other than plot devices, not real valid disabled people. And it was across the board of TV serials in the US: *Barnaby Jones; Starsky and Hutch; Cannon, Mannix, Banacek* and many others. I am being nostalgic, but there are other things making them the golden days of disability validation in TV representation.

It was an intended effort by broadcasters to challenge socially negative perceptions of people deemed different (blacks were another example). That, in itself, is not only astounding but admirable given the commercial demands of US TV and not something that happened here to any great degree. But, and this is what is most striking, the portrayals were about validation of disability and difference. This is now changing in the US and the same has become dominant in the UK – the invalidation of disabled. Why!

Well, with most disabled people now terminated (at least 90% in the case of spina bifida), infanticide common, and euthanasia routine and on the brink of being legalised, the whole attitude towards disability, difference and abnormality has changed. A change that is largely due to developments in technology, though not exclusively, that is now used to screen out rather than facilitate survival of disabled people. Popular TV has always tended to promote new social engineering philosophies; that is what it was in the 60s and 70s. Only then it was in our favour.

Looking good, feeling good

By Rosemary Batchelor

WE took 12 young people – including a young married couple – and four members of ASBAH staff to Churchtown in Cornwall.

For two of the younger ones, this was their first experience of staying away from home without their parents. Yes, there were tears at first and anxious phone calls from the parents, but 24 hours later everyone had found new friends and settled in.

The first morning's activity – involving the infamous Churchtown 'Death Slide' – was a real ice breaker.

Even some of the ASBAH staff were cajoled into 'having a go' – Margaret Stanton 'did it for Wales', I was bullied and Lynne Young, ASBAH adviser for Cornwall, actually enjoyed it. Liz Clayton sensibly was in charge of the camera and took a delight in snapping us at the point of no return.

The programme included something for everyone – yoga and reflexology and a session on body image were approached cautiously, but thoroughly enjoyed.

Fifteen-year-old Tina Morgan has a facial from The Body Shop

We visited the local maternity unit and looked at accessibility there. This was followed by talks on contraception and folic acid, and a video and discussion on personal relationships.

That evening (with parental permission) we rounded off an exhausting day with a showing of *The Full Monty* (complete with popcorn and coke!): a treat for all.

The next day, Tina enjoyed being the model for The Body Shop makeover, and the students and tutor from the local college photographic course took portrait photographs of everyone.

This was a real confidence booster and followed lots of discussion on hair, make-up and clothes etc, with the boys joining in as well.

That evening, Churchtown staff laid on a disco for us and another group which was there at the same time. ASBAH adviser Julie Knight joined us that day and we were especially pleased to see her for this very lively session!

A visit to the Churchtown working farm was a highlight of the week, and a chance for everyone to handle rabbits and guinea pigs and a cornsnake. There were hens and geese, calves and a pony, and a boisterous goat that was mistaken for a llama!

The last session was held in the mellow setting of the Manor House when Mair, one of the older participants, gave her account of leaving home and going solo. It was both a thought-provoking and lively session and much appreciated.

Twenty-six-year-old Tom Connell makes friends with the cornsnake at the working farm

Friday afternoon was soon upon us and time for reluctant (and tearful!) farewells.

The participants without exception enjoyed their week and are asking for more: we, the ASBAH advisers, were exhausted but wouldn't have missed it.

We are very grateful to the National Lottery Charities Board for making this very successful course possible by their generous funding under the Small Grants Scheme to Cornwall ASBAH, and to ASBAH adviser for Cornwall, Lynne Young, who ran the event.

● ***Rosemary Batchelor is ASBAH's senior adviser, health and policy issues.***

Kay Burgin prepares for the 'death slide'

Pupils' questions answered on disability

HARD on the heels of some successful school visits over the last few years, Leicestershire ASBAH (LASBAH) was invited to participate in a 'disability awareness day'.

Five members of the association – Carole Armour, Gareth Ferrin, Gary Siddons, Alison Twomlow and Lucie Dixon – attended the event, at Shepshed High School near Leicester, along with representatives of other disability groups and medical professionals.

The pupils looked at many aspects of disability, including access, making toys for disabled children and problems encountered by deaf and blind people.

LASBAH members visited the school's design department where they saw pupils building a textured picture for blind people. In the PE department, pupils played table tennis and other games sitting down instead of standing.

Throughout the day, LASBAH members discussed their personal experiences of living with a disability to four or five groups of 20 youngsters. Pupils asked about access to pubs, theatres, cinemas and shops, public transport, employment, housing and hobbies, plus many other questions.

Since this visit, in March, Carole Armour and Lucie Dixon made two further visits to Rushey Mead Comprehensive School in Leicester to talk about disability portrayed in the media, with discussions particularly centring around *EastEnders*, and the effect on brothers and sisters of having a child with a disability in the family.

"LOOK Uncle Frank, I'm running," said a little girl, who then sped off down the passageway in a trolley made by her dad.

These were the words that inspired Frank Mortimer to make thousands of similar trolleys for children with spina bifida around the world.

Last year, Frank was honoured by The Queen who awarded him the MBE for services to disabled people in Southampton. "It was a wonderful experience and quite emotional to think that the highest in the land was giving me an award for something that, to me, was quite natural."

Although Frank arrived at Buckingham Palace in a wheelchair, having suffered a stroke in 1995, he had made up his mind that he was going to walk the last few steps – albeit with a stick – to receive the award from The Queen.

"I was very proud to think it came to me. But my wife and family deserve part of the award because I would never have done it without them."

It was Frank's achievement in the mid-60s – helping to build a new type of mobility aid for children with spina bifida – which encouraged him to devote the rest of his life to voluntary work for disabled children, and which was recognised by his royal honour.

Frank and his wife, Yvonne, were two pioneers in the support network which was set up for families affected by spina bifida and/or hydrocephalus in the Southampton area and beyond. They attended an early meeting of national ASBAH in London and went on to help form many local associations.

Their eldest daughter Rosalyn, now aged 40, was born in 1957 with spina bifida and hydrocephalus, and was the fourth person in the UK to have the Spitz-Holter valve.

"We were very glad that she did because the operation was a success and made a tremendous difference to her life."

Frank and Yvonne wrote to John Holter in the USA asking how they might obtain the valve. They had to purchase it themselves, collect it from Heathrow Airport and deliver it to Westminster Children's Hospital. Rosalyn was the fourth child in the UK and the seventh in the world to have the operation.

"About 18 months later we were asked about joining ASBAH or to form a local group," Frank recalls.

"In Southampton, a leading light in the Spastics Society invited some of the parents of children with spina bifida in the area to a meeting to see if a group could be started." The South Hampshire group was formed, becoming known as SHASBAH – the name also given to the trolleys Frank produced.

SHAS

Frank and Yvonne helped to form groups in Southampton, Salisbury, the Isle of Wight, Dorcester and Bournemouth. Frank is a former president of Bournemouth ASBAH, and served as chairman of the Southampton group for many years before retiring in 1974 on being appointed chairman of the Southampton and District Federation of Clubs for the Disabled. At 82 years of age, he is still chairman of this federation today.

One of the Mortimers' early roles in the South Hampshire group was to visit families and it was during one of these visits that they met Debbie – the daughter of Ken and Mary Charrett.

"Ken had made a low trolley for Debbie so that she could be mobile about the house. It had so altered her life from an early age that it was decided that we should go into production for other children in our group," Frank said.

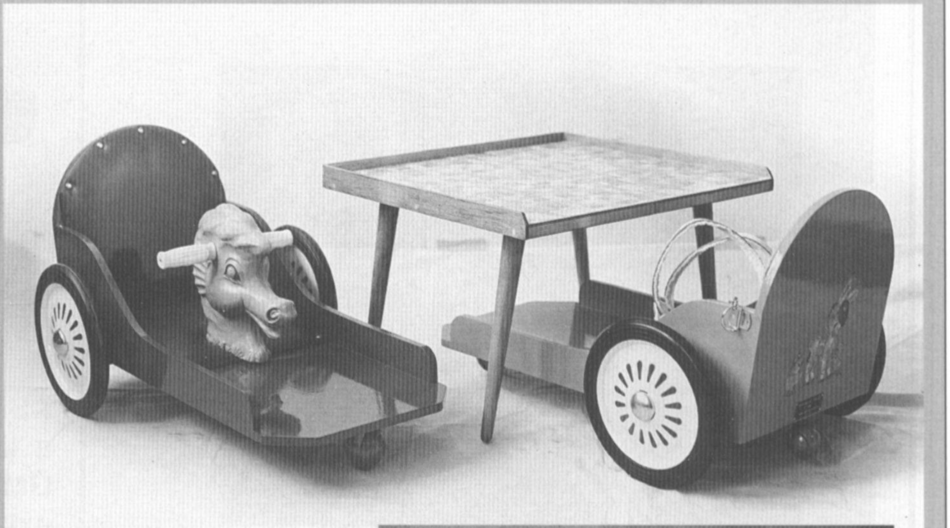
"News of our efforts soon spread and one of our first orders came from Westminster Children's Hospital, which put our trolleys on the map.

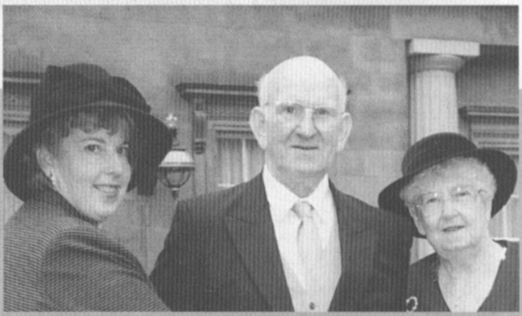
FRANK MORTIMER, who gave years of service to local ASBAHs has been awarded the MBE.

One of the most practical and far-reaching projects he was involved with – in the mid-60s and early 70s – was the building of the SHASBAH trolleys which motivated thousands of children all over the world.

***LIZ CAWTHORNE* reports.**

BAH trolley man awarded MBE





MAIN PHOTO: Examples of the famous SHASBAH trolleys, and a table, built by Frank Mortimer then sent to children with spina bifida all over the world.

INSET: Frank Mortimer after being presented with the MBE outside Buckingham Palace, with his wife Yvonne and eldest daughter Rosalyn.

"The Mirror sponsored 150 trolleys for children nominated by ASBAH and, apart from the UK, we sent our products to the USA, Australia, New Zealand, Germany, Argentina and elsewhere. The National Health Service became our main customer when we became an approved supplier. We went on to make other things as well for the hospitals such as various types of tables."

Patients at a local mental health hospital cut out the wooden pieces for the trolleys; Raleigh Industries supplied wheels and SHASBAH member Terry Brunger, who was also a blacksmith, made the axles. Other members helped with assembly. The finished product was always brightly painted.

"All the work was done by volunteer members of SHASBAH – Mary Charrett did the admin and I did much of the assembly and upholstery, fitted the wheels and axles, and packed them, often helped by my wife.

Frank was working at the post office at the time, mainly in the mornings, so he had afternoons free to make up the SHASBAH trolleys. But he was sometimes working until 11 o'clock at night to keep up with orders.

"The charge for a standard trolley, for children aged three upwards, was £5.50. We did a larger trolley for children up to 12 years old, for £10.50, because there was a need for it. Without the trolleys, many children could only crawl to get about.

"I was involved in making the first 2-3,000 trolleys. Another post office worker, who had a child with spina bifida, took the job over from me in 1974, and then production went to another association.

"The Speaker of the House of Commons of the time presented the 1,000th trolley ever made, and this was quite an occasion. It was a good period for doing voluntary work."

During his time as vice-chairman of SHASBAH, Frank took coach loads of families two or three times a year to the New Forest or the seaside.

"We took all the young mothers and fathers and their disabled children out for the day and it was a lovely affair.

"We still know a lot of the children, now in their 30s, many of whom go to the enclosure for wheelchair-users at Southampton Football Club, where my daughters Rosalyn and Anne are stewards."

GMTV superstar presenters Fiona Phillips and Eamonn Holmes

ASBAH will have our biggest opportunity in years to sparkle on British television when we join a mammoth fundraiser – the GMTV 'Get Up and Give' Appeal – in July.

For a whole week from 13 to 17 July, the spotlight will focus relentlessly on ASBAH and four other charities as we share the honours and the proceeds of this huge summer spectacular, now in its fourth year.

Under the guiding hands of GMTV's superstar presenters Eamonn Holmes and Fiona Phillips, once the eye of the nation is off football's World Cup final on 12 July, it will be on . . . US!

Day after day that week, millions of viewers switching on to the early morning breakfast show will find the five charities talking about themselves, our members showing how ASBAH made a real difference to their lives, and celebrities appealing to the public to pledge pots and pots of money.

Agony aunt and ASBAH vice-president Claire Rayner, Celtic footballer and Scotland international Darren Jackson (who last year had an operation for hydrocephalus following head injury) and TV celebrity Shaw Taylor have so far joined the list of celebrities who have volunteered to speak up for ASBAH.

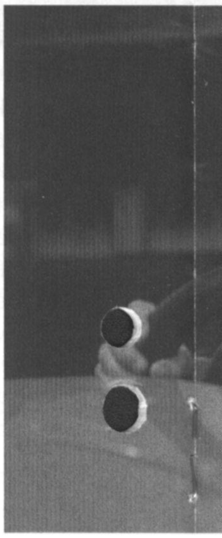
We have also found volunteers to help run the 190 telephone pledge-lines at BT central London. And – on Wednesday 15 July – ASBAH moves over to Alton Towers, the top theme park in Staffordshire, for a fantastic live TV show and day out.

Join A
Alton

ASBAH will be running a competition for a limited number of free tickets for the GMTV 'Get Up and Give' live television extravaganza at Alton Towers theme park on Wednesday 15 July.

Names will be drawn out of a hat once we have received our ticket allocation from GMTV. The only people who will be considered must promise to be there by 7am – or you won't get in.

Once in at 7am, you can stay as long as you like. Before Alton Towers wakes up fully and admits the public later in the morning, activity will be concentrated on the area next to the new, £12 million Oblivion ride. But winners of our competition can take a picnic and make a day of it!



Peak-season entry prices to Alton Towers, which attracts three million visitors a year, are usually £19.50 per adult and £15.50 per child.

Free tickets to the event, and similar ones like it during the week, will also be offered to GMTV viewers in the run-up to the Appeal.

The other charities taking part in the Get Up and
this year are the British Epilepsy Association, S
Association, AFASIC (the Association for All Spe
Children) and Contact the Elderly. Last year, eac
participating charities received £141,000.

If you would like to enter our draw for free tic
fill in the coupon on this page and send it by
Publicity, ASBAH, 42 Park Road, Peterboroug
ASBAH staff members will not be allowed
and there will be a limit of three tickets per f
The decision of the ASBAH appeals manager w

ASBAH at n Towers

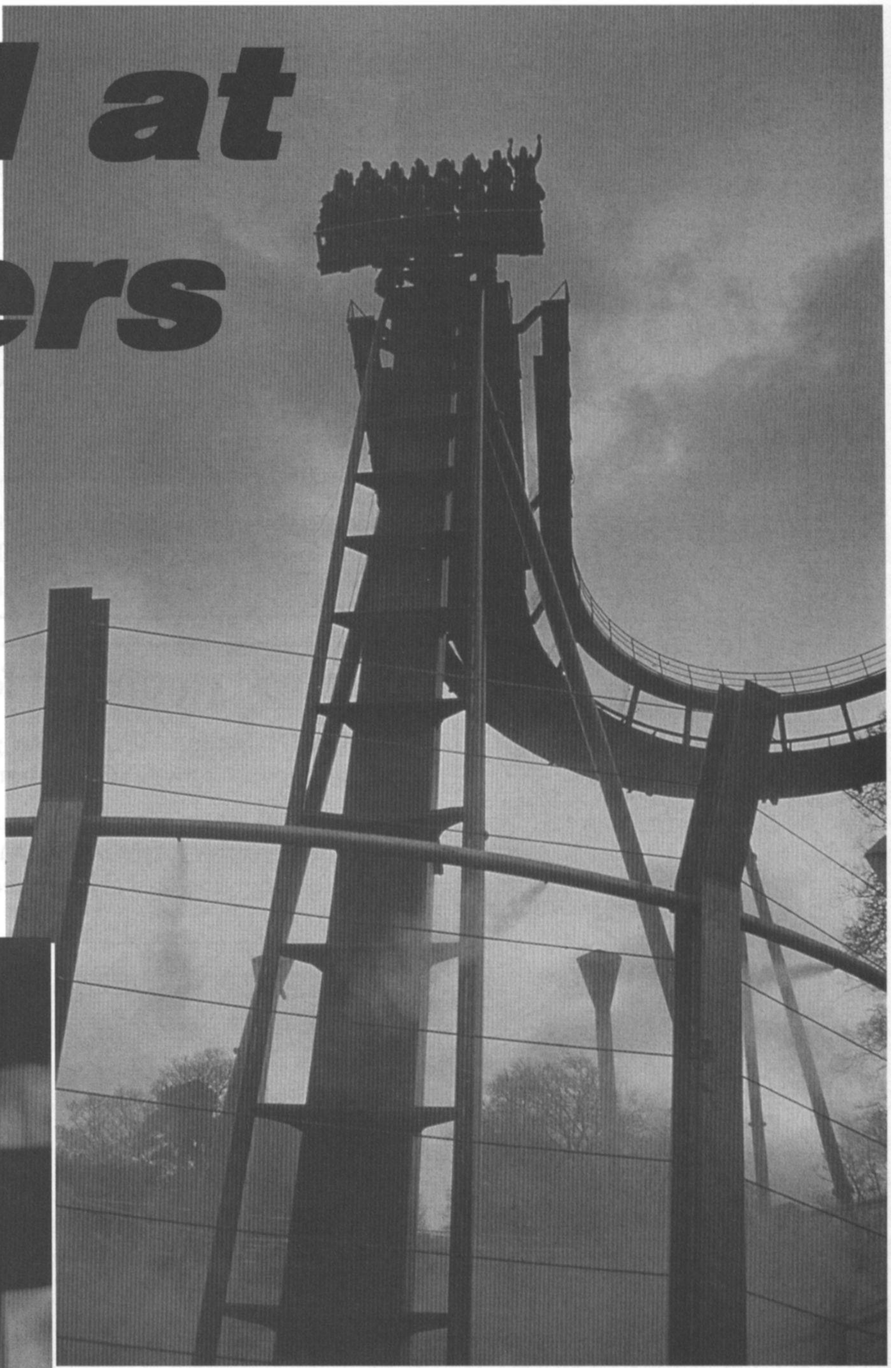
n for
the
ision
park

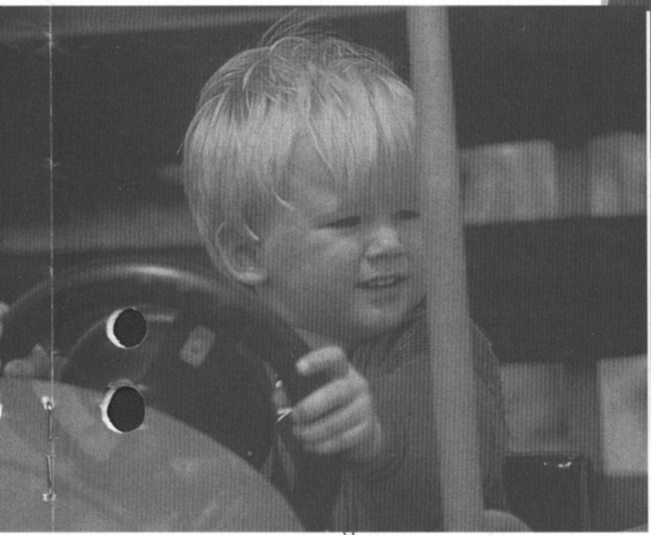
e we
from
l be
e by

u like.
dmits

GMTV

Get Up & Give





ABOVE: The new £12 million Oblivion – said to be the mother and father of all rollercoaster rides. LEFT: Fun for all the family including those not brave or big enough for Oblivion!

p and Give Appeal
ion, Spinal Injuries
ll Speech-Impaired
ar, each of the five

ree tickets, please
it by 30 June to:
borough PE1 2UQ.
owed to take part
per family group.
ager will be final.

YES! My family and I would like to enter the draw for free tickets for the GMTV ASBAH Day at Alton Towers on Wednesday 15th July. I understand if I win, I must be at Alton Towers by 7am in order to qualify for free entry.

Signed ____________________

Name ____________________

Address ____________________

____

Tel No: ____________________ **No. of tickets required (max 3)** __________

Independent living guide

A LARGE-print guide to help disabled people live independently is now available.

Although the book is produced by Disability North, the information could be easily applied to other areas of the country.

People benefiting from this book might be young people leaving their parents for the first time or older disabled people, perhaps leaving care.

There is more than 100 pages of information –mostly written by disabled people.

Independent Living *is available from: Disability North, The Dene Centre, Castle Farm Road, Newcastle upon Tyne NE3 1PH. Tel: 0191-2840480. The guide is free but a donation of at least £1 to cover postage costs would be welcome.*

Schoolboys' fundraise for ASBAH

A GROUP of school friends got together to organise a raffle, donate the prizes and sell the tickets to raise money for ASBAH.

Children as young as four years old bought tickets at 5p a time in a bid to win prizes of Easter eggs and sweets – all of which were donated by young raffle organisers, 11-year-old Paul Tibbs, Daniel Forcey, Christopher Smith, David Casey and Charles Hayes.

Paul's late baby brother Nicholas had spina bifida and hydrocephalus, and the Tibbs family were supported at the time of his passing, four years ago, by ASBAH adviser Elizabeth Miers.

Lynda Tibbs, of Willaston, South Wirral, said: "The boys worked very hard to sell the tickets and the children who bought them were extremely kind and generous as there were raffles for other charities to support at the same time."

Mrs Tibbs sent us a cheque for £32.86 on behalf of the boys in Prep 6C at Redcourt Prep School, Devonshire Place, Birkenhead.

Group will campaign for better car designs

CALL – Car Design for All – is a new group that has been created to press manufacturers to make cars more accessible and easier to adapt.

Graham Corbett, chairman of CALL and trustee of the Research Institute for Consumer Affairs (RICA), said: " Cars are mostly designed to appeal to the young and able bodied. CALL's message is that good design is good design for all."

DATES FOR YOUR DIARY

13 – 17 July

GMTV 'Get Up & Give' Appeal. Charities to benefit: ASBAH, British Epilepsy Association, Spinal Injuries Association, AFASIC, Contact the Elderly.

Wednesday 15 July

'Get Up & Give' Appeal, ASBAH Day at Alton Towers, Staffs. *See centre pages of this issue of Link for more details and the chance to win a free day out.*

18 – 25 July

Multi-activity course for people with learning disabilities, Calvert Trust, Little Crosthwaite, Keswick, Cumbria. £290 per person. *Tel: 017687-72254.*

Sunday 19 July

Disability Awareness Day, Warrington Disability Information Service, Walton Gardens, Warrington, 11am-5.30pm. Exhibitions, equipment, support groups, services etc. *Dave Thompson, 01925-655221, ext 3594.*

July – end of August

Share Music courses at the following venues (at different times): Calvert Trust, Keswick, Cumbria, and Exmoor, North Devon; Stackpole Trust, South Wales; Orpheus Centre, Godstone, Surrey; Cuisle Centre, Donamon, Co Roscommon, South of Ireland. *Dr Michael Swallow, 15 Deramore Drive, Belfast BT9 5JQ, tel/fax: 01232-669042.*

Monday 13 July

ASBAH South Beds Support Group, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, 01582-605749.*

14 – 16 August

The Northern Mobility Roadshow, Sheffield Arena, 10am-4pm. Wide range of production and adapted cars, converted vehicles, mobility aids, designer clothing, powered wheelcairs, 4-8mph vehicles, manual, sports and ultra light wheelchairs. *Carol Street, Sheffield City Trust, tel: 0114-243 5355.*

15 – 22 August

Multi-activity course for people with physical disabilities, Calvert Trust, Little Crosthwaite, Keswick, Cumbria. £290 per person. *Tel: 017687-72254.* Also on 5-12 and 12-18 September.

21 – 23 August

Parents in Focus, weekend for parents with disabilities and their families, information and social activities, at Valence School, Westerham, Kent. Cost: £25 per adult; £10 per child under 14; free for children under 18 months. *ASBAH South East Region, tel: 0181-449 0475.*

HYDROCEPHALUS NETWORK NEWS

ASBAH, 42 Park Road, Peterborough PE1 2UQ
Tel: 01733 555988 Fax: 01733 555985
Internet Web Site: http://www.asbah.demon.co.uk/
Reg Charity Number 249338

Summer '98

Shunt revisions may mean no driving for six months

FOR the first time, ventricular shunts have been mentioned in the *Medical Aspects of Fitness to Drive* – a booklet which is routinely consulted by doctors, who are asked by the DLVC to confirm that their patients are fit to drive.

The paragraph on shunts states: "Drivers who have had ventricular shunts inserted for the treatment of hydrocephalus must be advised to cease driving for at least six months to ensure that the risk of suffering an epileptic seizure falls to a safe level. Where procedures are undertaken to revise the extracranial portion of a shunt, there need be no restriction on driving."

Therefore, if you have a new shunt or the 'top end' revised, you must inform the DVLA.

There is no mention of third ventriculostomy in the booklet, but we would expect the ruling to be the same – that is, cease driving for six months after the surgery. Please confirm this with your neurosurgeon.

If you are unsure if this ruling applies to you, please contact DVLA Customer Enquiries on 01792-772151.

Fund-raising footballer

FOOTBALL fanatic Scott Ferguson met his sporting hero at a quiz night, which raised money for a specialist hospital.

The three-year-old met footballer Darren Jackson, who also happens to have hydrocephalus. Darren is back playing for Celtic and Scotland after his condition was helped by neuroendoscopy.

The Sport in Question night was organised by Scott's uncle Peter Martin – a sports presenter on Sky Scottish TV.

Scott's mum Cathy, from Motherwell, said: "We were reading your *Network News* about people raising money for research, and thought we would help Scott's hospital, which is Yorkhill in Glasgow.

"So, with the help of Scott's uncle, we had a Sport In Question night with sports celebrities. But the best bit for Scott was meeting his hero, Darren Jackson."


Scott with his hero Darren

The event raised £1,700 and a cheque was presented to consultant paediatric neurosurgeon Mr Carl Davis and Professor Dan Young at Yorkhill as a thank-you for all the care Scott has received.

Professor Young is honorary president of the Scottish Spina Bifida Association.

HNN contacts

Network Co-ordinator: Rosemary Batchelor 01733-555988.

Education (National): Petrina Noyes 01733-555988.

Medical (National): Julie Llewelyn 01733-555988.

Medical/Continence, (Eastern Region): Paula Thompson 01733-555988.

Medical/Continence (South East Region): 0181-449 0475 Caroline Berkley (Mon, Tues & Wed am). Gillian Yaz (Wed pm, Thur & Fri).

Education (North): Mike Dodd 01484-510202.

Medical (North & NW): Sue Ingham 0113-255 6767.

Education (Northern Ireland): Lorna Johnston 012477-72191

Medical/Continence, (Northern Ireland): Marie McGonnell 016487-64748.

Hydrocephalus (Northern Ireland): Lorna Johnston 012477-72191.

User-group forum co-ordinator (England & Wales): Jon Burke 0113-255 6767.

User-group forum project worker (Northern Ireland): Helen Clarke 01396-881898.

ASBAH's Hon Consultant on Hydrocephalus: Dr Roger Bayston MMedSci FRCPath, contact through ASBAH's Services Dept at ASBAH House.

Orange Badge success story

By David Nicholson
***Your Voice In ASBAH* member**

I APPLIED for an Orange Badge last November but received no response by the time my mother and I left for Canada to celebrate my mother's 85th birthday on Christmas Day at my sister's.

Whilst we were travelling, wheelchairs had been ordered for my mother at the airports, but at least three attendants asked me: 'why didn't you ask for a chair for yourself?'

On my return, I found a letter saying my application had been rejected on the grounds that: 'you can walk for more than 100 metres without stopping, severe discomfort, or help from another person.'

I rang up the manager who had signed the letter and pointed out that my application had clearly stated that, whilst I could walk for well over 100 metres on a flat surface, I would almost come to a halt on uneven ground, and could not attempt to go down a flight of steps without a hand rail.

In response to her comment that local car parks were on ground level, I said that two main off-street car parks were at the top of a hill and on the other side of the river, whilst most off-street car parks in nearby villages are more than 100 yards from the centres.

Before I had even given the matter further thought and written to the client relations officer, I heard by phone that my application for an Orange Badge had been granted.

So, if you have hydrocephalus, don't be put off from appealing against rejections of your applications for an Orange Badge or similar benefits.

Staff profile

AREA ADVISER AND SPECIALIST ADVISER (MEDICAL/CONTINENCE), SOUTH EAST REGION, GILL YAZ ....

has joined a karate class, following in the footsteps of her seven-year-old daughter, Angela.

Though still a white belt, Gill likes the idea of being in control of her body and in tune with its movements.

"In the karate class I go to, you learn the kicks and the punches, but it is taught as a non-contact art."

Now that she works full-time for ASBAH – as part-time area adviser for N & E London and part-time specialist adviser – Gill finds it more of a challenge juggling work with caring for her two children. But she does find time to tend a fairly large garden.

My job as a nanny

by Jayne Leigh

WE'VE received one reply, so far, to our request for people in full-time jobs to write in with their experiences.

Jayne Leigh, aged 28, was diagnosed as having hydrocephalus soon after birth and had fits until she was 16.

After school and college, Jayne started working with disabled children – a job which she still does. She now lives by herself in a flat in SW London.

"I went to a mainstream school until I was 12 and then changed to a special school in Chatham, near where my parents lived.

Then I went to college where I first did a two-year course with the YTS. Then my parents moved to Devon and I moved with them.

I went back to college for a further two years to do the 'Family and Community Care Course.'

I had to learn many things including first aid and home nursing – both passed with credit.

I had to work with the elderly and the handicapped on the course. I also worked with children with Down's Syndrome, and in many nurseries as this is what I wanted to do as my main job.

After a lot of hard work, I finished this course with credits and passes, of which my family were very proud.

I am now and have been for many years a full-time nanny. I am currently looking after a little girl, aged one. I have been doing this job since she was four months old.

I passed my driving test on the second attempt. I learned to drive with BSM. It was quite hard work, but I managed it. I really didn't think I would do it.

Going to college and learning to drive were really hard times but I got through them.

I now live by myself in London in a rented flat – yet another thing I wouldn't have thought I was going to do.

I have many friends here in London and we all go out at weekends.

Although I am a bit slow at times, I've managed to do a lot in my life so far.

Shunt linked to phone problems

INCOMING telephone callers have noticed a break-up of words spoken at the other end by their friend, who has a shunt.

Gwen Bayley, from York, contacted BT thinking there was a fault with the line or her equipment. But three changes of telephone equipment and numerous rewiring procedures made not the slightest difference.

Then a chance remark from her daughter, who works with computers, set Mrs Bayley thinking.

"My daughter was calling from Holland. She experienced break-up of speech from my end, and suggested I placed the receiver to my other ear."

Miraculously, the situation corrected itself. Mrs Bayley's shunt is situated on the right side of her head and is 10 years old, and this led to automatic assumption – could the shunt be responsible?

"My cousin is an ex-BT engineer who, on hearing of my experience, said the problem I described was usually present when there is some metal involvement," Mrs Bayley continued.

"Is there any metal in the shunt?"

Network co-ordinator, Rosemary Batchelor, replies: I have not heard of the problems with shunts and telephones which you describe, but can confirm that a Spitz-Holter shunt does contain a metal 'spring', so your cousin's theory could be correct."

What's in the June/July Link

GMTV Get Up & Give Appeal . . . . . p3 & 14-15

Staff news p4

Benefits win p5

Who's being 'bipped'? _ p7

Wheelchair centre changes course after ASBAH acts . . . p9

Kent's Lottery win . . p10

Cornwall course p11

HN News p17-24

Dave's Diary p27

Link is ASBAH's main magazine. Subscription details from National Centre.

● *TAKE Care of Yourself* is the title of a new booklet and information pack following the theme of this year's National Carers Week. They are available from: ***National Carers Association, 20/25 Glasshouse Yard, London EC1A 4JS.***

NEWS ..... NEWS ...... NEWS ...... NEWS ......

● A NEW range of oversized keyboards connect directly to the keyboard socket of a standard PC.

The keys are enlarged to allow use via head pointer stick, stylus or feet. The keyboard also speaks when a key is pressed and an LCD displays the key selection for deaf users.

More details from: Mervyn Edwards, Electrocoustic Limited, tel: 01264-333664.

● A WIDE range of tools to make life easier for anyone who has difficulty in using standard gardening equipment is given in a new book.

Each piece of equipment is described and illustrated, and the names and addresses of suppliers is included.

Gardening – an Equipment Guide ***is £7.50 (UK); £10 (overseas) from: Disability Information Trust, Mary Malborough Centre, Nuffield Orthopaedic Centre, Headington, Oxford OX3 7LD. Tel: 01865-227592.***

● ANYONE planning a holiday, short break or day trip this summer can get valuable ideas on places to stay and things to do in Cheshire from a popular guidebook.

The free *Cheshire Welcome Guide* has been produced by Cheshire County Council and Cheshire Disabilities Federation and has been fully updated for 1998. It is designed to give disabled and elderly visitors reliable information on access and facilities at the county's tourist attractions and accommodation.

The guide lists over 100 attractions and 30 accessible places to stay, all of which have been graded under the English Tourist Board/Holiday Care Service National Accessible Scheme.

The guide is easy to read and understand. Each venue has been inspected by the Cheshire Disabilities Federation.

To get a copy of the guide, which is also available in large print, call 01244-604127.

Hydrocephalus group developments 'down under'

THERE have been a few changes to a group in Australia called HEAD – Hydrocephalus: Education, Action and Development.

Firstly, it has changed its name due to confusion about the group's responsibilities. It is now the Hydrocephalus Support Association, which gives support to people with hydrocephalus and their families.

Referrals are still being made to the group and there is a committee consisting of longstanding members.

There are set membership fees for individuals, families and groups. The charges are: $15 per year for people with hydrocephalus or related conditions; $25 per year for families and a minimum of $5-$10 per year for professionals and students. If you would like to join, please make out a payment to the 'Hydrocephalus Support Association' and send it to the address below.

Penelope Wilkinson
Secretary/treasurer
Hydrocephalus Support Association
13 Hosking Crescent
Glenfield
New South Wales 2167
Australia

True story

by Sister Valerie Malone
St Joseph's, Rush,
Co Dublin

DEBBIE Sanderson's words: "I believe that a shunt revision has a profound effect on your body," profoundly affected me. Her *True Story* in *HNN*, Winter 1997, inspired me to write to you.

I had a shunt fitted, and a brain tumour removed, in April 1985. There were nine shunt revisions from 1985-97.

During this time I acquired other medical conditions. Due to a pleural effusion – the result of an over-active shunt – I developed chronic pleurisy.

Debbie tells us that her periods stopped. Mine started coming fortnightly, weakening me so much that I had to go to bed for a few days during each period. My GP prescribed the contraceptive pill; the problem resolved itself.

My shunts work too hard and too fast causing great pain. A remedy is painkillers, which certainly help. In 1995, I developed irritable bowel syndrome (IBS).

An article in *Reader's Digest* November 1997, quotes research linking painkillers to IBS.

I flew to Rome for studies in summer 1997. In December, my shunt started leaking out of the back of my head. Tests and a shunt revision were performed in Gemelli Hospital, Rome. Staff and facilities were excellent.

However, I developed hypertension, raised blood pressure. I am 42 years of age.

How many tests are there examining possible links between irregular ovulation and shunt users? Is the *Reader's Digest* article correct? How many other shunt users have developed high blood pressure? Where can one find answers to these questions? Or are there surveys showing such research is unnecessary?

In the Summer '97 edition of *HNN*, Sarah Williams writes: "I feel very bitter that doctors dismiss the symptoms of hydrocephalus so readily, and people are left to suffer ... before receiving ... treatment ... they deserve and need."

Do you know the worse thing about shunt revisions for me? The tests and waiting? The pain involved? The costs? The worry to family? No, none of these things.

It's not being believed. All too often, I'm sent for a CT scan. Things 'image' fine, and I go home, tail between my legs. The ensuing drop in self-esteem is hard to handle.

I go through this scenario several times when my shunts fail, before, eventually, being sent for surgery.

Sister Valerie Malone

Do people who are hydrocephalus-free have any idea what it's like to have shunts malfunction? To "just know" within oneself that things are not right? Yet scan results are "all clear." Possible consequences making for awesome responsibility!

Thankfully, shunt leakage was a clear indication that something was amiss in Rome!

As a missionary I spent 18 months in New York. When headaches and fleeting lapses in vision re-appeared, I was referred to a neurosurgeon and hospitalised.

Tests included a "shuntogramme". A piece of equipment, separate from CT/MRI scanners, this shuntogramme measures body fluids. It is used, for example, to diagnose the exact amount of fluids in arthritis sufferers' joints.

It's also used to diagnose shunt function. A small amount of infra-red dye was injected into my shunt. A screen showed the dye travel through my shunt. Seeing the dye stop doctors could pinpoint where the blockage was.

Isn't it high time such accurate diagnostic equipment for shunt users was available in Ireland and Britain?

IN response to Jane Procter's True Story (*HNN*, Spring '98) about the delay in her son being referred to the specialist hospital when he had a suspected shunt problem, we have an agreement with our local GPs and the neurosurgeon that we can take our son Keith to the specialist hospital he is under. This was the same when he was at the children's hospital.

The system is this: if your child is having fits, you take your child to the local hospital to control them, and the local hospital phones the specialist hospital they are under, telling them that he/ she is coming in.

But at NO TIME let the local hospital interfere with the shunt unless they know what they are doing.

We were always led to believe that the specialist hospital at which you are a patient cannot refuse to see you.

You may also be able to get a police escort to take you there.

Another problem is likely to be encountered by parents when their children go from childhood to adulthood.

When our son was 18 and had a fit, the children's hospital would not accept him because he was over age.

Questions should be asked about what's going to happen when your child becomes an adult before s/he reaches 16, so you are prepared for it.

Ken Little
Bexley
Kent

HNN co-ordinator Rosemary Batchelor says: ***Mr Little has raised some important points. Not all areas provide such a good service, so it is advisable to check with your neurosurgical unit to see if they have an "open door" policy and, if not, what is their procedure for people with shunt problems.***

And remember to find out about transition to adult clinics well before your son/daughter is due to be discharged from the paediatric clinics. This can be from 16 years upwards.

OUR 12-year-old son James was diagnosed as having hydrocephalus at eight months old.

Due to having a shunt fitted when he was so young, we were told that his skull has not grown in line with his brain and therefore is a tight fit.

When he was seven years old, James suffered with terrible headaches but we were continually told that his shunt was working as it should, and we were sent home from hospital.

We knew something was not right, so we insisted on talking to my son's consultant.

My husband expressed our concerns and frustrations that we felt James was suffering needlessly, and insisted that his case be looked at again.

The consultant agreed to perform a sub-temporal decompression procedure on James, which entailed removing a small section of bone from his skull just above his temple.

The operation was a success and the headaches ceased. We understand that the procedure allows relief area within the skull to alleviate increases of pressure and prevent headaches.

James had further problems three years ago when the bone that had been removed began to grow back and the operation had to be repeated. James is well at present but, as every parent of a child with hydrocephalus knows, you take a day at a time and dread those terrible words: 'Mum, I've got a headache.'

We understand this procedure is not performed nationwide. We would like to hear from any other parents who have had experiences regarding the above procedure and how it has affected their child.

Keith and Wendy Weavin
The Chalet, Laurel Lane
Halesowen, West Midlands
B63 3DA

MY son Daniel, aged seven, had a problem of over-draining when he was five. His last shunt was renewed at two and a half years.

He has Sanamigran in the evening for migraines. He still has daily headaches – some only slight. He is sent home from school a lot and the headaches tend to get worse when he is getting a cold or any illness.

Does anyone have any information about how to deal with these headaches?

Mrs Julie Procter
36 Ingleton Drive, Hala
Lancaster LA1 4RA

HN NEWS letters

MY DAUGHTER Amy is having a few problems with her shunt. Whenever she jumps up and down, for example, on a trampoline, she gets sharp shooting pains at the site of insertion. She has not shown any signs of shunt malfunction because of this and has had no real problems since the shunt was inserted at two months of age.

Playing on the trampoline is one of Amy's favourite pastimes and I have been unable to find out if this would be harmful to her or would affect the shunt in any way.

I'd be interested to know if anyone else had this problem and how they dealt with it.

Karen McCumstie
PO Box 298
Derby
Western Australia 6728

I READ with interest and feeling the account by Mrs Scrimshaw (*HNN* Spring '98) of her son's problems with his shunt. I share her concerns about many GPs not understanding the hydrocephalus shunt system.

My son was born in 1966 and also had the Spitz Holter valve fitted. Mark, like Stephen Scrimshaw, was looked after very well during his school years but, as soon as he reached 18 years of age, there was nowhere he could be checked for all his disabilities. It was a series of different hospitals for each problem.

About 18 months ago, Mark began to get very tired and depressed with no energy. He struggled to work but would come home and that was his day. He had no energy for any social life. I took him to our GP where they could find nothing wrong. In December 1996, he had a brain scan to see if they could find what was causing his headaches and lethargy, but the scan came back clear.

In 1997, he started getting problems with his left hand – he could not grip properly and was finding it difficult to do certain things for himself such as doing up buttons and putting his watch on. We went to our GP four times but, like Mrs Scrimshaw, were told 'no' they didn't think it was his valve. Due to his depression, Mark was seen by a psychiatrist, who advised that Mark didn't need a psychiatrist but perhaps a counsellor. Mark had counselling sessions fortnightly for about six months.

Meanwhile his hand was deteriorating. We saw the GP again who set up six sessions of physiotherapy, which didn't seem to do any good at all.

So we went back to the GP, who then got us an urgent appointment with a rheumatologist who, after examining Mark for about five minutes, could tell it was a neurological problem. He could see Mark had muscle wastage in his left hand and was lacking one of his reflexes (his left biceps reflex).

The rheumatologist arranged an urgent appointment with a consultant neurologist for Mark and things have moved very fast since then. Mark had an MRI scan on 27 January and was admitted to the Atkinson Morley Hospital in February, where he underwent an operation. Mark was found to have a Chiari Malformation which can cause some spasticity of the left hand and side of his body.

We still have a long way to go but, hopefully, Mark will be able to resume work by June.

I don't blame GPs as they are all overworked, but I do think practices should be aware of what specialist clinics are available so, when problems arise in patients with multiple disabilities, they can direct them to their nearest clinic.

I have since found out through national ASBAH that there is an adult SB clinic at the Westminster & Chelsea Hospital. I blame myself for not finding out sooner, but we all tend to trust our GPs. In future, if I suspect anything is going wrong, I will not hesitate to telephone ASBAH.

Mrs Diane Phillips
Sunningdale, Ascot, Berks

Editor's note: *Chiari Malformation is a secondary effect of spina bifida, and can also be found with hydrocephalus. It is where the lower parts of the brain fall or are pushed into the upper part of the spine.*

Darren Pattison

True story

**by Jennie Pattison,
Goole, East Yorkshire**

HELLO, I am the mother of a five-year-old boy with congenital hydrocephalus. We have had a very rough time but have now, hopefully, 'come out the other side' of a very dark tunnel. I wondered if our story would give hope to other families undergoing similar problems.

Darren was diagnosed when he was eight weeks old. We were sent to a neurosurgeon a fortnight later. Unfortunately, during this time his condition had got worse. So what we thought would be a short consultation turned into immediate admission and surgery two days later to insert a VA shunt.

We were in total shock, we didn't really know what hydrocephalus was and what it was going to mean to our every-day lives. We were just busy 'getting on with it.'

During that year, Darren had six revisions up to the time of his first birthday. He had shunt blockages, infections and, at one time, the hole was too big, so the fluid seeped around the shunt and caused a 'sausage effect' along the shunt tube in his neck.

Luckily, we changed to an excellent neurosurgeon who took some muscle from Darren's neck to fill the gap. After this had been done, 'touch wood', we have had no more problems.

Needless to say that all the time spent ill and in hospital did affect Darren's development. As soon as the shunt problems were rectified, his development went from strength to strength. And we will soon be celebrating four problem-free years and look forward to many more.

Darren still has a minor problem with balance and co-ordination and cannot walk for long distances when he needs to use a large buggy. But, believe me, it is a very small price to pay.

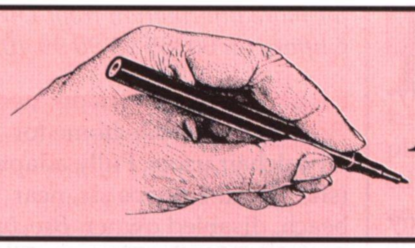
Darren is a very happy, chatty – he could 'talk for England' – little boy. He wakes up singing and goes to sleep singing, as well as singing most of the day. He has given endless joy and purpose to our lives. We would not be without him. His quality of life is very high. He is a 'happy chappy', although not an angel – just a little boy!

He has just been assessed for statementing and been awarded Band 5 with 10 hours support, plus PE time, playtime and dinner times which he manages very well with. He loves going to school and is progressing beyond our expectations. I just hope he continues to prove wrong the people with dark sounding prognosises, and doubting Thomases.

Thank you ASBAH for your continuing support and supplying endless information. I find *HNN* very interesting and love to read the *True Stories*. It's nice to hear some good news.

Annual subscription rates (four issues a year) are: £2.00 (UK); £5.00 European and overseas suface mail and £10.00 by airmail.

***New subscribers should send payment to:
Lynn Thomas, ASBAH Services Dept,
42 Park Road, Peterborough PE1 2UQ.
Cheques should be made payable to
'ASBAH'.***



Letters

We invite letters for publication. Send them please to: *Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ.* The Editor reserves the right to edit letters for publication, so keep them as short as possible.

THERE were a number of new mums in the magazine recently. That was me 22 years ago, also a new mum and in *Link*.

My husband and I are wheelchair-users – John through polio (from aged five) and me with spina bifida.We married 23 years ago and Anna was born 11 months later.

We have done the lot ... coped with measles, mumps, chicken pox and glandular fever (just before exams!); attended Brownies, Guides, swimming galas, music concerts – you name it, we were there. Add riding and skating to the list and you can imagine how much time was involved.

We had holidays in Skegness in the early years, then became more adventurous and added Italy, Portugal and Florida.

We dealt with exams, tests and boyfriends. We fed and supplied one floor of the halls of residence during the first year at university – well, it seemed that way from the requests for jam and washing powder etc); sat with proud grins on our faces through the graduation ceremony and waved goodbye when our beautiful daughter left to start work as a diagnostic radiographer in Selly Oak Hospital, Birmingham.

It is hard to believe that so much time has passed since we first saw that tiny baby and realised she was ours. You have to be very committed to turn that baby into a decent adult, and it is <u>hard</u> work.

We made it and have a daughter we can be proud of. I wish the same for all the other mums – good luck.

Susan Seager
Pickering
North Yorkshire

PS Please ask Mr Deryck Brown if he is going to insist on an accessible loo on all Mr Branson's planes!

THERE is no doubt in my mind that, yes, Lynda Howard is a 'Mum in a million' and her daughter, Alexandra, like me, would be the last to disagree. However, I must take Lynda to task regarding her statement: "At the time, people asked me how I could justify raising several thousand pounds for one child when the same amount would have helped a larger number of children. .... If the money had been spread across more children they would each have been helped in a small way for a short time."

This is simply not correct. There are dozens of non-governmental organisations out of the UK and hundreds all over the world, spreading their efforts in alleviating suffering, handicaps and poverty; training local volunteers; improving the standards of training for local professionals such as doctors, teachers and nurses; and working on changing the attitudes of parents, institution directors and care staff – all this within the country of need, mindful of their culture and religion.

Removing one child from a bad situation makes no impression on the situation. Only by tackling the problems within the country, and by devoted professionalism over a long period of time, can a really worthy, long-lasting solution be put in place, to help all the others left behind by the 'mother in a million.' In this business, 'several thousand pounds' would help a lot of children for a long time.

Donations, please, however small or large, to the Al Hussein Society for the Rehabilitation of Physically Handicapped Children, sent to the Director at PO Box 5102, Amman, Jordan.

M A Stephens – unpaid volunteer 1994-1998, Al Hussein Society Outreach Programme for children with all disabilities, PO Box 5102, Amman, Jordan

---

MY name is Geoff. I am 39 and have spina bifida (meningomyelocoele) and hydrocephalus, and live an independent and active life, although I am 'in between' jobs at present.

My interests are playing and listening to music, socialising and personal/spiritual development.

I'd be very pleased to hear from anyone – individual males and females, parents, families, non-disabled people – who would like to make contact by phone, write or get together.

I don't know of any networks or organisations relating to SBAH, so I'd love to hear from anyone who does.

Geoff Miles
15A Stainsby Avenue
Heanor
Derbyshire DE75 7EL
Tel: 01773-534124

FOR SALE

Electric wheelchair, Invacare Storm xc1265. Dual control, kerb-climbing ability, battery and charger. Ideal for large person. Hardly used. Cost £4,500, will accept £2,800 ono. *Tel: 0181-686 7376 (Croydon).*

Volvo 340 Automatic (Blue). Hand controls, and wheelchair carrier for disabled person, £2,750. *Phone: 01797-230067 or 222076.*

Sungift 350 mobility scooter, 20 months old, hardly used, £1,200 ono. Sudbury area (Suffolk). *Mrs Wild, tel: 01787-210375.*

Self-washing and drying Chiltern Closomat toilet. Free to good home. Three years old. Has been maintained by the council; would need checking over and installing by electrician. *Tel: 0181-841 1312.*

Concern for Comfort 3ft bed. Fully adjustable with massage therapy. 9 months old. Immaculate condition. Cost £2,650 new – will consider reasonable offers. *Tel: 01438-213919 (Stevenage, Herts).*

Concern for Comfort 3ft bed Fully-adjustable, buff-coloured mattress, bought 18 months ago but good as new. Cost £2,500 new – will consider £1,750. *Tel: 0181-440 3971 (Cockfosters, Barnet, Herts).*

Ford Escort 1.6 Encore, £9,500. Auto, 3-door, March '97, 1,500 miles. Constable attendant carchair and lift system fitted to passenger seat. *Enquiries to Mrs Roberts, tel: 01283-713671.*

HOLIDAYS

ISLE OF WIGHT ASBAH – Fully-equipped, wheelchair accessible, two-bedroom bungalow. Sleeps six. Clubhouse, indoor heated pool, shop etc. Lovely views, many interesting places to visit. Own transport advisable. *Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983-863658.*

WEYMOUTH BAY – Fully equipped, wheelchair-accessible caravan – sleeps five; on Haven Holiday Park, full use of all facilities – heated indoor & outdoor pools, bars, children's club & full entertainment programme. Three miles from Weymouth. *Details from: Margaret Humphreys, tel: 01494-714270 (Bucks & E Berks ASBAH).*

SELSEY, West Sussex (SASBAH) – Fully equipped, purpose-designed for wheelchair access, mobile home. Sleeps six, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. *Details from Mrs B Nunn, tel: 01903-763473.*

FRANCE, Western Dordogne – Picturesque barn conversion in idyllic rural location. Ground floor fully wheelchair accessible, comprising living areas, large double bedrooms and spacious bathroom. Level access to sun terraces, garden and pool. Two further bedrooms and bathroom on first floor. English owners live locally. *Phone for more information from Duncan Clifford on 00335 53 90 99 40.*

FRANCE – Ile d'Oleron, near La Rochelle – Mobile home for wheelchair users. Fully adapted (shower etc), sleeps six, near beach, disabled owner. *Brochure from M Mardle, Fricourt, Filey Road, Old Heath Road, Southminster, Essex CM0 7BS. Tel: 01621-772447.*

MAR-Y-SOL, TENERIFE – Wheelchair accessible apartments. Heated pool with hoist. Restaurant, pool-side bar, equipment hire. Sunshine guaranteed all year round. *Ring today for cheapest prices. Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX, tel: 01753-685718.*

ALGARVE, PORTUGAL – Wheelchair friendly luxury villas with swimming pools, or small friendly hotels with adapted rooms. *Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX, tel: 01753-685718.*

ORLANDO, FLORIDA – House with a heart for disabled travellers! Spacious, luxury, adapted bungalow situated on golf course. Three double bedrooms, two bathrooms (Mangar bathlift installed), Cable TV, free local telephone calls, free Country Club membership. 24-hr 'on-call' management company. 15 mins Orlando Airport. 20 mins Disney. Paraplegic owner. *Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT, tel/fax: 0161-792 3029.*

ACCOMMODATION

Sheltered accommodation in self-contained flats for single people with physical disabilities. *If interested, contact: Miss Linda Patton, Head of Home, Cheshire House, Kinsale Park, Waterside, Co Derry, N Ireland. Tel: 01504-341861.*

Vacancy in Flat 1C Wharfedale, Ben Rhydding – part of shared unit for three people at Five Oaks. Wheelchair-friendly. Staff support 10am-3pm daily. 24-hr cover by mobile warden. 30 mins by train from Leeds and Bradford. *Contact: Mark Best, tel: 01943-603013.*

Letters Extra

I HAVE met a women in her early 30s who has been informed that she has the Chiari deformity following a number of tests, including MRI scan.

She does not have hydrocephalus or spina bifida but suffers from severe headaches, numbness in her arms and neck discomfort.

Her surgeon has said that he can operate to alleviate these symptoms but she is very worried at the thought of having surgery and would like to make contact with someone who has the same diagnosis and/or who has undergone this surgery.

If anyone can help, please contact:

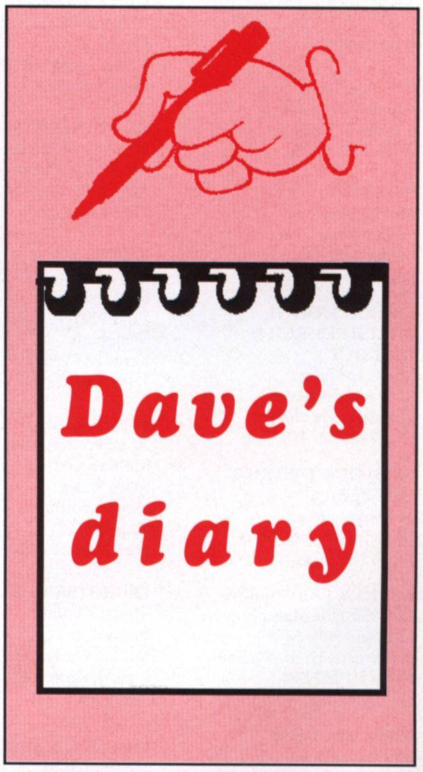
Diane Morgan
ASBAH adviser (Bromley, Bexley, Croydon & Sutton),
ASBAH South East Region,
Tel: 0181-659 3060

NAISH HOLIDAY VILLAGE, NEW MILTON – Clifftop park with "excellent" status at New Milton, Hampshire. Excellent site facilities within 100 yards, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible log cabin accommodation, Sleeps six, well-furnished. Free club membership.

GRANGE COURT HOLIDAY VILLAGE – Park with "good" status at Goodrington Sands, Devon. Excellent site facilities within short walk, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible, mobile home. Sleeps 4-6, well appointed. Free club membership. (Purchased with funds from the National Lottery).

MILLENDREATH HOLIDAY VILLAGE – Excellent seaside site with good facilities, just outside Looe in Cornwall. Restaurant, clubhouse, indoor pool. Fully-equipped, and fully wheelchair accessible, two-bedroom chalet accommodation. Sleeps six – well-furnished and comfortable. Free club membership.

Details: Mr P Cash, tel: 01425-672055 – Bournemouth Spina Bifida Association, registered charity number 261914.



Dave's diary

I'm too used to answering people's questions. From doctors and the DSS down to market researchers and strangers, people believe that because I'm disabled they are entitled to have me answer by form, by questionnaire, or in conversation every stupid question (including personal or financial ones) they can think of. Worse, I've accepted their right to ask!

Benefit reviews like the BIP, to me, are witch hunts. It seems to me we are considered guilty of fraud unless proved otherwise. I may be paranoid, but I doubt that as much effort will be put towards adding eligible people to the list, as whipping them off. In *Lifestyle*, the Motability magazine, the DSS was interviewed about the Benefits Integrity Project. Asked about cutting Disability Living Allowance, the reply was: 'Nobody has anything to fear .... unless they have something to hide." I'm not convinced.

Who asks the questions and decides what is 'hidden'. That's what I'm afraid of! BIP assessors need to understand what they're asking about. There seems a profound and worrying lack of medical training and/or general knowledge amongst BIP assessors, if reports are to be believed: one genius reportedly asked someone how long they'd had Down's Syndrome! (Clue: it's congenital). I'm sure that's a one-off. But, when the flow of my money depends on such people, it's no wonder I get hot under the collar. Another reason for steam is that while hairs are being split by BIP assessors about who should get their forty or fifty quid a week, how many *billions* have been lost through chronically over-budget military contracts (Nimrod, Trident, etc)? I don't know but, I think, we should be told. After all, if they've nothing to hide, they've nothing to fear!

David Fulford-Brown

LINK Rates

Link ISSN 1360-323X
Editor: Liz Cawthorne

Published by **ASBAH**,
ASBAH House,
42 Park Road,
Peterborough PE1 2UQ
Telephone: 01733 555988.
E-mail: lizc@asbah.demon.co.uk

LINK SUBSCRIPTION
6 EDITIONS – 12 MONTHS

UK	£4.80
Europe and Overseas Surface Mail	£7.50
Air Mail	£15.00

All payments should be made in Sterling.

Classified Rates: £3.75 for 30 words max;
£5.25 for 30-45 words;
£6.25 for 45-60 words.

Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of *LINK* (August) should be submitted by Friday, 10 July. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

DIRECTORY OF INDEPENDENT LOCAL ASSOCIATIONS

AFFILIATED ASSOCIATIONS

BARNSLEY
Mr Geoff Jenkinson
12 St Leonard's Way
Ardsley, Barnsley
S Yorks S71 5BS
Tel: 01226 292546

BEDFORD
Mrs M Simmonds
16 Parkstone Close
Bedford MK41 8BD
Tel: 01234 400068

BOURNEMOUTH, CHRISTCHURCH & DISTRICT
Mrs G Lanning
23 Seaway Avenue
Christchurch, Dorset
Tel: 01425 273 255

BRISTOL & DISTRICT
Mr G Egan
64 Rookery Road
Knowle, Bristol BS4 2DT
Tel: 0117 9777942

BUCKS & EAST BERKS
Mrs Margaret Humphreys
15 Brackley Road
Hazlemere, High Wycombe
Bucks HP15 7EW
Tel: 01494 714270

BURY & BOLTON
Mr David Clyne
51 Cuckoo Lane, Whitefield
Manchester M45 6WD
Tel: 0161 798 7804 (after 4pm)

CAMBRIDGE & DISTRICT
Mrs P Woodhead
111 Wingfield, Orton Goldhay
Peterborough PE2 5TJ
Tel: 01733-234304

CHESTER & DISTRICT
Mrs P Ithell
34 King Edward Street
Shotton, Deeside
Clwyd CH5 1DW
Tel: 01244 811074

COVENTRY
Mrs N Newman
11 The Earls Court
Cheylesmere
Coventry CV3 5ES

DERBYSHIRE
Mrs A Hewitt
St Merryn, 20 Burley Hill
Allestree, Derby DE3 2ET
Tel: 01332 841893

DUDLEY & WOLVERHAMPTON
Mrs Lorna J Wootton
14 Leveson Road
Wednesfield, Wolverhampton
West Midlands WV11 2HF
Tel: 01902 738724

GRANTHAM
Mrs J Asken
88 Goodliffe Road
Grantham, Lincs NG31 7QB
Tel: 01476 401643

GREENWICH & DISTRICT
Mrs M Mears
29 Wellmeadow Road
London SE13 65Y
Tel: 0181 244 3526

HAMPSHIRE NORTH, W SURREY & S BERKS
Sue Washington
Mole Cottage, The Oaks
Hawley, Camberley
Surrey GU17 9BE
Tel: 01276 609135

HERTS AND SOUTH BEDS
Lorraine Watson
75 Saturn Way
Highfield
Hemel Hempstead
Herts HP2 5PA

HUDDERSFIELD
Mr Stephen Bolton
361 Bradley Road
Huddersfield HD2 1PR
Tel: 01484-424479

KENT
Mrs S Stevens
6 Croftside
Vigo Village
Meopham
Kent DA13 0SH
Tel: 01732 822985

LEEDS & BRADFORD
Anna Waddington
Mullion Cottage
Main Street
Hawksworth
Guiseley
West Yorks LF20 8NX

LEICESTERSHIRE
Mrs A Twomlow
29 The Crescent
Market Harborough
Leicestershire LE16 7JJ
Tel: 01858 432967

LINCOLN & MID LINCS
Mrs P Malson
"Pinfold"
Chapel Lane
North Scarle
Lincoln LN6 9EX
Tel: 01522 778781

LINCOLNSHIRE SOUTH
Mrs P Mason
67 Boston Road
Heckington
Sleaford
Lincs
Tel: 01529 460322 (after 6pm)

LONDON N WEST
Mrs H Prentice
37 Milton Road
Hanwell
London W7 1LQ
Tel: 0181 579 4685

LONDON SOUTH
Mrs S Cudd
15 Woodvale Walk
Elder Road
W Norwood
London SE27
Tel: 0181 761 2400

NORTHAMPTONSHIRE
Mrs Alison Walter
12 Adam Avenue
Northampton
NN1 4LQ
Tel: 01604 34419

OXFORDSHIRE
Mrs Shirley Dale
14 South Row
Chilton
Didcot
Oxon OX11 0RT
Tel: 01235 834785

PRESTON
Mrs S Thompson
34 Beatty Road
Southport
Merseyside
PR8 6LB
Tel: 01704 542589

St HELENS & DISTRICT
Joanne Barrett
10 Halefield Street
St Helen's
WA10 2DE
Tel: 01744-612860

SHEFFIELD
Mrs Celia Nicholson
36 Church Street
Oughtibridge
Sheffield S35 OFW
Tel: 0114 286 2993

SOMERSET
Mrs J Eastley
46 Hamilton Road
Taunton
Somerset TA1 2ER

SOUTH THAMES
Mrs Margaret Holmes
24 Hawthorn Road
Dartford
Kent DA1 2SB
Tel: 01322 290570

SOUTHAMPTON & DISTRICT
Mr S J Fitzgerald
32 Ellis Road
Thornhill
Southampton SO2 6ER
Tel: 01703 402644

STAFFORDSHIRE
Mrs J Davies
8 Oakhill Avenue
Oakhill, Stoke on Trent ST4 5NJ
Tel: 01782 845365

STAINES, HOUNSLOW & DISTRICT
Mrs Pamela Page
237 Upper Halliford Road
Shepperton
Middx TW17 8SP
Tel: 01932 783991

STOCKPORT & TAMESIDE
Ms Christine Walker
8 Elm Court, Maplecroft
Offerton, Stockport
Cheshire SK1 4JY
Tel: 0161 429 9042

SUNDERLAND
Mr J Pounder
42 Gowanburn, Fatfield
Washington
Tyne & Wear NE38 8SG
Tel: 0191 415 1725

SURREY
Alan Twyford
86 Tolworth Park Road
Tolworth, Surbiton
Surrey KT6 7RH

SUSSEX
Mrs M White
Averys, Rusper
Horsham
W Sussex RH12 4PR
Tel: 01293 871217

TRAFFORD & SALFORD
Mrs T Gaynor
Davis Court, Cyprus Street,
Stretford
Manchester M32 8AX
Tel: 0161 865 0222 (am only)

WARRINGTON & DISTRICT
Miss Nancy Gleave
16 Hilltop Road
Woolston, Warrington,
Cheshire WA1 4PD
Tel: 01925 819329

WESSEX
Mr T Poole
123 Gerrards Green
Beaminster, Dorset DT8 3EA
Tel: 01308 862614

WIGAN, LEIGH & DISTRICT
Mrs Pat Stridgeon
24 Greendale Crescent
Leigh WN7 2LQ
Tel: 01942 676091

WIRRAL
Mrs M Appleyard
28 Stavordale Road
Moreton
Wirral, Cheshire L46 9PR
Tel: 01516 784409

WORCESTERSHIRE
Mrs G Doleman
9 Pelham Road
Droitwich
Worcs WR9 8NT
Tel: 01905 775 862

YORKSHIRE NORTH
Miss Faith Seward MBE BA
45 The Paddock, York YO2 6AW
Tel: 01904 798653

WALES

Llanelli
Mrs Anthea James
61 Westland Close
Loughor, Swansea SA4 2JT
Tel: 01792 895020

Mid Wales
Mrs J Carter
12 Lambeth Close, Craven Arms
Shropshire SY7 9QY

North Wales
Mrs V Conway
4 Ewloe Drive
Bodnany Road
Llandudno
Tel: 01492 878225

South Wales
Mrs Brenda Sharp
4 Lakeside, Barry
S Glamorgan CF62 8SS
Tel: 01446 735714

NORTHERN IRELAND
Mr J Rippey
Long Eaves
24 Tulleywiggan Road
Cookstown
Co Tyrone BT80 8SD
Tel: 0164 87 62290

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde
Mrs Diane O'Hagan
83 Boothley Road
Blackpool
Lancs FY1 3RR

Calderdale
Mr A L Crowther
12 Elm View
Huddersfield Road
Halifax
HX3 OAE
Tel: 01422 341497

Cannock & Walsall
Mr Ken Hall
17 Wallhouse Street
Cannock, Staffs
Tel: 01543 504847

Chesterfield
Mrs K Tomlinson
23 Hathern Close,
Brimington Common
Chesterfield, Derbys
Tel: 01246 272724

Cornwall
Helen Youngman
13 St Petry, Gears Lane
Goldsithney, Penzance
Cornwall TR20 9LA
Tel: 01736 710261

East Anglia
Mrs L Turner
7 Stow Gardens, Wisbech
Cambs PE13 2HS
Tel: 01945 466205

Essex
Mrs R McCarthy
26 Brixham Gardens
Ilford, Essex IG3 9AX
Tel: 0181 594 1852

Isle of Wight
Mr D J S Sprake
Springfield, Town Lane
Chale Green, Ventnor
I W PO38 2JS
Tel: 01983 551234

Lancaster, Morecambe & District
Mrs Dyson
25 Royds Avenue
Heysham, Morecambe LA3 1PA

Nottinghamshire
Mr Allan Barratt
127 Limetree Road
Hucknall
Notts NG15 6AW
Tel: 0115-953 7291
Fax: 0115-953 2081 (8am - 6pm)

Rochdale
Mrs Anne Lawton
20 Spencer Street, Chadderton
Oldham, Lancs
Tel: 0161 6524487

Whitchurch (Salop)
Mrs E Calder
Southfork
Sedgeford, Whitchurch
Salop SY13 1EX
Tel: 01948 663627

OTHER ASSOCIATIONS

SCOTTISH SBA
Executive Officer:
Mr Andrew Wynd
190 Queensferry Road
Edinburgh EH4 2BW
Tel: 0131 332 0743

IRISH ASBAH
Ms Claire Gill
Hon Secretary, Irish ASBAH
Old Nangor Road
Clondalkin, Dublin 22
Tel: 003531 4572326

JERSEY, Channel Islands
Mrs Mollie Buesnel
Villa Acacia
Sunshine Avenue
Five Oaks, St Saviours
Jersey JE2 7TS

Association secretaries requiring changes to this list should contact: ***LINK EDITOR, ASBAH, 42 PARK ROAD, PETERBOROUGH PE1 2UQ Tel: 01733 555988 Fax: 01733 555985.***